

Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

Technical Document -

Chapter 4.1 Literature Review – Family Carers

Nick LeMesurier; Research Fellow,
Niyati Bathia; Research Associate,
Shoumitro Deb; Clinical Professor of Neuropsychiatry and Intellectual
Disabilities, and
Gemma L. Unwin; Research Associate

Correspondance to:
Shoumitro Deb, MBBS, FRCPsych, MD,
University of Birmingham,
Division of Neuroscience,
Department of Psychiatry, UK.
Email: S.Deb@bham.ac.uk

www.ldtransitionguide.bham.ac.uk

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This chapter provides a discursive summary of selected literature, arranged by theme. As has been described in the relevant section in the chapter, the literature on transition and mental health for young people with learning disabilities is not extensive, though there would seem to have been a recent increase in the number of guides available. What effect such guides have perhaps remains to be seen, their influence being determined to no small degree by the authority they are perceived to have and the way they are publicised. As far as we are aware, their effectiveness in changing practice and their influence on the lives of people with learning disabilities is generally unmeasured and unrecorded.

The experience of family carers of children and adolescents with learning disabilities and mental health problems

Introduction

While a good deal of research has involved family carers as research subjects much has been based on convenience samples drawing upon the experience of family carers of children who are in contact with services or certain voluntary organisations (Grant & Ramcharan, 2001). The literature on care giving is thus (of necessity) mainly qualitative and somewhat skewed in the direction of carers of relatives who are more disabled and / or use services. There is also a degree of emphasis on the negative consequences of caring for a disabled relative, as these are ‘problematic’ for services. Less is known about those families who do not use services, such as those from minority ethnic communities whose take-up of services is recognised to be low, or those families who contain at least one member with mild learning disabilities. The literature dedicated to the experience of parents who are carers of children and adolescents with learning disabilities and mental health problems is far from extensive. Much of this is dedicated to explorations of mothers’ experiences: that of fathers is almost non-existent.

This review is organised under a set of thematic headings. To a large extent these overlap. Qualitative research is by definition exploratory in nature, many closely related issues often emerging in the process. Distinctions in this review are presented to reflect the main emphasis within the papers described.

The pathology of caring.

In a useful review of the literature on family carers, Grant & Ramcharan (op cit) point out the emphasis that has been given to what they describe as the pathology of caring, in particular the practical and psychological problems involved in maintaining on-going support. Various models of caring are suggested: the ‘wear and tear’ hypothesis (Birenbaum 1971, in Grant & Ramcharan 2001), is one which describes processes of network shrinkage as the child ages, with consequent increases in stress for those ‘left behind’. By way of contrast – or at least of qualification - Grant & Ramcharan note the ‘adaptation’ hypothesis, which describes the way families adjust to care-giving over time and tend to grow in terms of skills and reciprocal relationships, even when

objectively measured networks are shrinking (Seltzer & Krauss 1989; Grant 1993 in Grant & Ramcharan, op cit).

Coping with stress

Certainly, carers of people who are heavily dependent do have to learn to manage stress and to cope with a range of opportunities that may be different from, and probably more limited than, those of their peers who do not care for a severely disabled person. As people go through their life-course, one way by which they adjust to situations is by changing their cognitive appraisals of them. Thus, potentially threatening situations may incur changes in the nature and structure of “interpersonal relationships, perceptions of family support, family finances and care giving histories” (Grant & Ramcharan op cit). Indeed, discussions of the way family members adjust and adapt their own family histories to help them ‘place’ events within a life story provide an interesting and valuable counterpoint to the rather negative and potentially stereotyping view of parents as merely passive recipients of welfare services or even as contributors to the dependency and limited development of their relative.

Kim, et al (2003) compared the effects on emotional well-being of coping strategies used over time by mothers of adult offspring with learning disabilities and additional mental health problems with those of mothers of adult offspring with learning disability alone. They found that the care-giving role produced a number of stresses, especially for those mothers of offspring with additional mental health problems. It was found that these mothers were more likely to use ‘emotion focused’ coping strategies than mothers of adults with learning disability alone. For mothers with sons or daughters with learning disabilities only the use of ‘problem focused coping strategies’ over time reduced subjective levels of burden and depression and produced better relationships between the adult. For mothers of adults with additional mental health problems, the use of problem focussed coping strategies improved relationships with their son or daughter but did not lead to changes in depressive symptoms and feelings of burden. The authors suggest, rather half-heartedly, the use of support groups as a means to help families use more problem-focused coping strategies and to learn new techniques of coping as they experienced increasing feelings of burden and depression. How effective these are likely to be is unclear. Also, such a response assumes that support groups are likely to be available. It ignores issues of social inequality, pro-active forms of resistance to official power often being associated with more middle class and urban environments (see Riddell et al, 2002, Pascall & Handy, 2004).

White & Hastings (2004) used multiple measures of support to correlate parental well-being with a sample of 33 parents of adolescent children with moderate – profound learning disabilities. They correlated measures of parental well-being (stress, anxiety, and depression, and care-giving satisfaction), social support (informal and formal sources and practical and emotional support) and child characteristics (adaptive and problem behaviour). They found that parents tended to seek help from professional sources for their child’s (rather than their own) needs. Informal sources of social support were positively correlated with higher levels of parental well-being.

Positive aspects of caring

The accounts that parents themselves provide may offer a more uplifting account. A recent book written by the mother of four children with ASD / Asperger’s syndrome

(Row, 2005) provides an engaging description of her struggles to gain official recognition of her children's needs and thus access to special education provision. Her book is intended as a guide to other parents in similar situations, and apart from its advice on strategies needed to deal with official intransigence, its main message is one of courage and resilience in the face of bureaucratic obstinacy.

Locating the mechanisms that contribute to such strengths, Grant & Ramcharan describe Turnbull et al's (1986, 1988) reference to "intra-psyche or spiritual qualities (i.e. love, strengthened faith, tolerance and sensitivity, and patience) suggesting a re-appraisal of life's purpose" as a source of reward.

Expectations and realities

In a programme of semi-structured interviews with 190 informal carers of people with learning disabilities of all ages in North Wales, McGrath and Grant (1993) measured the association between support networks and levels of dependency and behaviour problems. They found behaviour problems and high stress levels associated with adolescence, which coincided with declining levels of informal support that continued throughout the life-cycle. Carers of adolescents exhibiting behaviour problems were particularly vulnerable. The authors also found that contact with professionals tended to decline after adolescence, such help being sought from and 'replaced' by other family members.

In a programme of research undertaken to investigate the effectiveness of transition planning for young people with complex and highly individualised needs leaving a large independent school in the Midlands, Smart (2004) found a number of discrepancies between the priorities expressed by parents and those of professionals. Parents valued "atmosphere and environment" above the "work experience and further education" advocated by professionals. 44 parents / guardians were interviewed. They were clear about the positive and negative aspects of adult placement: "Where parents were happy with the current placement they tended to list certain aspects as positive, just as parents who were unhappy with the placement tended to list the opposite extreme. This suggests high agreement between parents as to what is important to them and their child." (Smart, 2004b)

Positive aspects of placement	Negative aspects of placement
"Near to family home" "Large outdoor space/good leisure activities" "Opportunities for independence and education" "Skilled and motivated staff" "Good ethos" "Understanding of challenging behaviour" "24 hour/one-to-one specialised care" "Regular staff and residents meetings" "Improvement of communication skills"	"Far away from family home" "Insufficient stimulation/ education/social opportunities" "Too 'PC' - letting young people do as they like as they are adults" "High staff turnover" "Lack of communication between placement and home" "Management of behaviour using drugs" "Withdrawal of respite for one non-residential placement"

Parents of children with disabilities want the same things for their children as do parents of children without disabilities – a good home environment, leisure and work opportunities, independence and choice. Petry et al (2005) cite as applicable the model of Felce & Perry (1995, 1996a,b) to distinguish five domains of quality of life divided into several sub-domains: (i) physical well-being (health, personal safety, fitness, mobility); (ii) material well-being (finance and income, housing quality, transport, security and tenure); (iii) social well-being (personal relationships, community involvement); (iv) development and activity (competence, productivity and activity) and (v) emotional wellbeing (positive affect, fulfillment–stress; mental health, self-esteem, status and respect, faith and belief, sexuality) (Felce & Perry 1995, p. 53, in Petry et al, op cit).

The move from ‘childhood’ to adult status is one that is undertaken not only by the young person himself or herself. Parallel to this is the journey many parents make at the same time as certain new, and sometimes unsatisfactory, roles are engaged. For some, this may involve a loss of status and of role as the young person they care for is pushed across an invisible threshold, changing identity overnight and acquiring a nominal autonomy that may have little to do with any actual changes in their behaviours, outlook or capabilities at the time.

Todd and Jones (2005) argue that, for parents themselves, transition can mean a continuation, and even an extension of their parenting roles well into adulthood and old age. Such a continuation is often unexpected by parents, who may be unprepared for the change in levels of service provisions available for their son or daughter, or for the change in role expected of them. The authors examine in some detail the experience of mothers of adolescents with LD during the ‘middle years’ of parenting, taking a life-course perspective, and drawing upon a series of 30 in-depth interviews with mothers of teenage children with learning disabilities. Their paper places the relationships between parents’ own understanding of their roles as care-givers and their sense of self in a more dynamic context, and finds that while some mothers welcomed the continuation of motherhood, many suffered a profound sense of loss. They refer to a ‘biographical time bomb’, noting that in the early years of parenting mothers closely allied their experience with that of parents of non-disabled children. In the middle years, however (roughly corresponding with their offspring’s teenage years) they (along with their offspring) became aware that their experiences and their expectations are different from the norm. Many mothers found they experienced a loss of personal identity and role commensurate with an increase in their responsibilities. The authors’ rather gloomy prognosis involves a withdrawal rather than expansion of personal opportunities and an indefinite period of care-giving involving increasing burden.

McConkey & Smyth (2002) interviewed 34 school leavers with SLD and their parents to explore and compare perceptions of risk. They present a cognitive model of risk taking that consists of four key components:

- **Competence:** an activity such as being left in the house on their own will be viewed as a much greater risk than for those young people who have proven they are able to cope with danger.

- Consequences: The degree of risk is related to the extent to which the activity brings positive or negative consequences.
- Conditions: The expectation of negative consequences is related to the conditions under which an activity is performed and the presence and the effectiveness of resources to facilitate help.
- Collaborators: The opinions of other (respected) people can also help to influence perceptions of risk. McConkey & Smyth (2002, pp27-28)

The authors argue for an approach to risk on the part of professionals that recognises both the parent's and young person's concerns and builds upon their strengths through education and training, rather than simply seeking to avoid negative consequences. They suggest that assessment of risk should take into account the conditions under which an activity takes place, and allow for adjustment of thresholds depending on the safety factors that are present, thus avoiding the 'all-or-nothing' approach to decision making with a graded and gradual plan of developing greater self-reliance in the young people.

The 'professional' roles of parents

Undoubtedly, the nature of caring for sons or daughters with learning disabilities is different from that experienced by parents of children without disabilities (though there are important overlaps). Parents of severely disabled offspring may be required to act in the 'professional' role of representative well beyond the common legal threshold of adulthood.

Trends in policy (see DH 2005) and mechanisms such as the In Control Programme¹ and Direct Payments (DH 1996)² by which personal care services are commissioned and funded by individuals using grants from their Local Authority, emphasise the role of the service user and their representatives as a 'professional', a status that many parents of disabled offspring are familiar with, but which takes a new dimension with financial accountability added to their concerns.

It may be too soon to describe the effects of this change, or to determine whether such mechanisms really have introduced the benefits of a free market into what was (and to a large extent still is) a state run monopoly. Early signs are that take-up of Direct Payments amongst adults with all forms of disabilities is low (DH 2005). Williams et al (2003) point out that, while the idea behind Direct Payments is simple, in practice it is complex to negotiate. They argue that the revised Policy & Practice Guidance on Direct Payments (DH 1999) indicates that in order to receive Direct Payments, people must be 'willing and able to manage them alone or with assistance.' On the face of it, this places many people with learning disabilities at a disadvantage, unless they have appropriate support. For many, family carers are significant providers of that support.

Their research with family carers of people with learning disabilities (many of whom did not use words with which to communicate) found that a wish for independence and opportunities for their son or daughter to make their own life was common across

¹ (<http://www.in-control.org.uk/>) 2 Feb 06

² <http://www.dh.gov.uk/assetRoot/04/08/10/38/04081038.pdf> 2 Feb 06

all parents. Far from obstructing moves towards independence, they actively sought opportunities, and recognized and welcomed some degree of risk as a necessary part of growing up. Many of the parents in their study were not aware of the Direct Payments scheme, even though it had been available from local authorities since 1996, and local authorities were made obliged to offer it under the new Direct Payments Regulations (DH 2003). While some expressed concern at the extra workload and responsibilities involved, others saw it as liberating them and their son or daughter to choose the staff they wanted and arrange support to suit their needs and circumstances: "...when there is more power to go round, then everyone can benefit." One mother said: "...it has helped me to be a mother again, and not just a carer." (Williams et al, op cit, p227)

Pascall and Hendy (2004) present a discussion on the socio-political factors that facilitate the achievement of key measures of independence – jobs, housing, education, social relationships – for young people with (mainly physical) disabilities. They describe a trend within the political environment of the last three decades that has emphasized individual parental responsibility for the welfare of children with a duty to seek or remain in employment. The result has been an "ambivalent model of family support" that has promoted the family as the primary social unit in which responsibilities for child welfare are contained, and at the same time withdrawn state support, forcing families – and especially mothers - to 'juggle' employment and family commitments. Those young people who had achieved independence in the form of professional careers, own housing, education, extensive social networks and so on, ascribed their success largely to the influence of "exceptional parents" who actively encouraged their children's acquisition of skills and an 'independent attitude'. These young people were very much in a minority in the sample, and tended to come from relatively well to do backgrounds. They had the kind of parents that are perhaps envisaged by the creators of social policies that promote individual influence over social responsibility. The authors place the issue of social inequality in sharp relief:

"Only those with the most resourceful and resourced parents were likely to access jobs and independent living...this will have been at the expense of those with the least resourceful and resourced parents, whose needs for more support in and beyond their families were painfully clear..."
(p 162)

Parents vs. professionals: Parents of disabled children are likely to find themselves having to take on roles and to develop skills and knowledge that are at least as great as those of professionals. Yet a recurrent note in this literature is the mismatch between the perspectives of parents and those of professionals (Orlowska 1995; Case 2001; Clegg et al, 2001; Grant & Ramcharan, 2001; Goupil et al, 2002; Williams et al, 2003; Riddell, et al, 2003, Ward et al 2003, Todd & Jones, 2003; Smart, 2004; Row 2005; Todd & Jones 2005;). Clegg et al (op cit), for example, undertook an in-depth study to compare the experiences of a small group of parents of children with severe learning disabilities whose challenging behaviours had persevered after a move to adult services with a similar group whose behaviours had not. Each group displayed similar levels of behaviour prior to transition. In a trenchant comment they note that

“Moving from school to adult services is not a psychological but an institutional transition that occurs within varying policy contexts” (p152).

This is true and well worth emphasising, though it is also true that there is a psychological dimension to transition that affects young people with learning disabilities and their families alike. Their study set out to create a model to compare and contrast the way staff and parents perceived transition and how the challenging behaviour of their offspring affected communication between carers and staff in adult services. They found that differences between the way staff and parents perceived transition was much greater than they had anticipated, so much so that they prevented the development of a common model based on a triangulation of views. Indeed, they comment:

“A model of transition triangulating staff and parent views eluded our grasp, because there was so little overlap between their views. Moreover, the major issue underlying analysis was not presence and absence of challenging behaviour, as had been expected: this was a pertinent dimension, but differences between staff and parent perspectives were more germane to the material.”
(p. 155)

The authors devise the concept of the ‘Reluctant Referee’ to describe parents’ experience at transition of being forced to take responsibilities for important decisions without sufficient information or knowledge, and of mediating between professionals and their family, including the young disabled person himself or herself. They found that staffs from adult services working with these young people were unlikely to value or read written reports outlining previous experience and the person’s life history. Indeed, such staffs tended to assert the notion of transition as an abrupt change from childhood to adult status, on the basis of advocating ‘normalisation’. Parents, on the other hand, tended to see far less of a difference in the behaviour and the abilities of their son or daughter. The gulf between parents and services is exacerbated by “a culture that places adult autonomy above partnership practices with parents,” for which it would seem policy, rather than individual practice, solutions are required.

Clegg et al (2001) cite Twigg’s (1992) research, which records “a distinct intellectual disability view of carers held by British service providers.” Parents are as likely to be seen as a problem as they are a solution and a resource:

“[Parents are]...perceived neither as resources, co-workers, nor co-clients...but as ‘superceded’. Staff treat the ‘superceded carer’ as if they should not be present and will soon not be, even though more than 50% of adults with a learning disability continue to live with their parents.”
(Clegg et al 2001)

Todd & Jones (2003) explored the unequal power relationships between mothers and professionals, noting that many mothers are reluctant to portray themselves as having any needs of their own beyond the caring role. Though they generally are willing to advocate on behalf of their offspring as part of their parental role, they may fear that any expression of their own needs and aspirations will be seen as selfish. Contact with the professional world is often problematic, ranging from encouragement on the part of professionals to reject their children at birth or in the early years, to stigmatization

on the basis that they are merely ‘neurotic’ in drawing attention to their child’s difficulties and in asking for extra help (see also Row, 2005).

Case (2000) reasserts the gloomy scenario of conflict between parents and professionals. In studies with members of an acknowledged pro-active support group, he found evidence of dissatisfaction with the attitudes and dominance of professionals, who were perceived to remain in control of the parent-professional relationship, acting as ‘experts’ and failing to engage with parents as equals in decision making. A subsequent study with the same group (Case 2001) found evidence of a shift in the power balance. The reasons behind this were not explored, though Case cites Dale (1996) in suggesting that, perhaps the explanation lies in “a greater degree of authority (being) given to parental knowledge and decision-making, with parents becoming more assertive, aggressive, demanding and critical of the professionals who deal with their child.” (Case 2001 p846)

Participation: Though recent legislation in the UK has reinforced parents’ rights to be involved in crucial decision-making processes, the extent to which they are so varies enormously. Riddell et al (2002) compares and contrasts the extent of parental involvement in the statementing and recording of special educational needs in two English and two Scottish local authorities. Proceeding from the view that “the ways in which parents of children with SEN and professionals negotiate their subject positions is based on the idea that policy is not simply made by elected representatives nor in public fora, but also in the daily interactions and negotiations of service users and professionals,” (p 412) they found that considerable power lay in the hands of professionals. For example, decisions on who receives a Statement of Special Educational Needs were made entirely by the local authority. Though parents might receive copies of all assessment reports, they often did so too late to consult or to arrange for further action. Parents were always recommended to send their child to the local mainstream school, without other options being presented. Though routes to appeal did exist and parents could be informed of them if meetings with officials did not achieve conciliation, many parents found these routes unappealing. Officials tended to try to justify and reinforce the efforts of the local authority rather than help parents to seek alternatives. There was little redress to independent advocacy.

In their assessment, policy in England afforded parents greater power than that in Scotland, where the process is described as often “adversarial” (p424). While some parents in both the English and Scottish samples were engaged with the processes, and resisted the ascribed role of passive consumer, many parents had to adopt the role of “critical consumer” if they were to exercise any power. This was hard to do in the absence of support groups or other structural means by which the power of officials could be challenged.

Orlowska (1995) presents a thorough review and discussion outlining the complexity of participation:

Participation is more complex than selected statements of intent can reveal. Relevant are a variety of factors from the perspectives of both families and services. Families have a range of past experiences of professionals, expectations of services, expectations for their son or daughter’s life, practical constraints on their time and energy and a variety of levels of knowledge, confidence and power. In turn, services

operate under different levels of demand, resource constraints, ideologies about care provision and perspectives on family and user participation(p437-8).

Without power, participation for any individual or group(s) is meaningless. Power itself depends upon certain preconditions: the capacity to understand options and choose between them; being in roles in which power can be exercised and for those roles to be in networks such that the exercise of power is effective (Drake 1992, in Orłowska, op cit).

Participation can take many forms, whether it is on behalf of individual family members or a group of known individuals, or for a larger population:

[Participation] can occur in a wide variety of guises including participation in formal planning and consultation exercises, participation in campaigning on individual, local or national issues whether as an individual or as a member of a parent group. Participation can include the setting up of a new type of service outside the bounds of what already exists, replication of existing models or obtaining additional resources, complaining about services or, wishing to see inappropriate services close (see Brown et al., in press). It can cover campaigning for the retention of service models which are no longer thought appropriate by some professionals in the field (see Frohboese & Sales, 1980) and can result in service creation (see Brandon, 1990) and also inadvertent replication of aspects which a new service had been designed to avoid (see Kalifon, 1991).
(Orłowska, p 441)

A significant obstacle to the participation of parents as equals to professionals is the effect of competing interests. Some parents are willing and able to devote considerable time to voluntary participation in various groups and services as well as pursuit of their own son or daughter's welfare. Not all are able or inclined to do so, and there is a danger their experiences, wishes and views are overlooked.

Unless they withdraw completely from participation with professionals, parents are likely to find themselves having to take on any number of roles by default. Transition is a time when these roles become increasingly complex and contested. They may include that of advocate, decision maker or case manager. Established patterns and expectations of participation are no longer usable, and critical decisions have to be made and a range of new professionals and agencies negotiated with (Turnbull, 1988). Such relationships can be stressful. In a survey of 42 family members of young people with SLD, Thorin & Irvin (1992) found interaction with residential service providers and the difficulties of getting residential services of good quality to be among the most stressful (in Orłowska, 2001). Where relationships with professionals have been negative in the past parents may delay decisions concerning transition to adult services, or avoid it altogether until such time as a crisis occurs.

The need for information: A number of papers advocate access to information as an essential resource in parents' armoury. Yet, information is often hard to come by. Service systems are complex, and those without the opportunity to learn how to navigate them are at a disadvantage. Information is not just a discreet resource: it also encompasses knowledge of how to communicate with and access support from professionals, how to negotiate the benefits system, and how to argue with and

advocate for their offspring. ‘Information’ thus encompasses issues of confidence, experience, human and social capital and support.

In her review of the literature on the information needs of young people with LD and their families at transition Townsley (2004) devotes a section to Transition and the Family. She cites various studies that have emphasized the importance of working closely with families (e.g. Rowland Crosby et al, 2002; Smart, 2004) and acknowledges the fact that families are frequently absent from the transition planning process (Morris 2002 in Townsley; McNair & Rush 1991).

Townsley (2004) provides a valuable review of the literature on the information needs of young people and their families at transition. They note that transition for young people with learning disabilities who use services is not a straightforward matter:

“(It) is not simply a case of moving from one set of organizations targeted at children to a parallel entity concerned with adults. The reality is that the two sets of services tend to be organized in very different ways and to have very different sets of cultures”(see Heslop et al, 2002).

The value of parents in the transition role has been highlighted by a number of authors (McNair and Rusch, 1991; Blacher, 2001; Hendey & Pascall, 2002 in Townsley, op cit), who see the involvement and support of the family as a whole as important.

Tarleton & Ward (2005) undertook a programme of research with young people with learning disabilities and parent carers who undertook a number of focus groups exploring their respective information needs. The aspirations of these young people – who did not include people with severe learning disabilities - mirrored those of non-disabled peers, and included access to further education, to independent accommodation, leisure, relationships and social opportunities, money and autonomy. Parents were concerned at the prospect of transition, and were largely unaware of what the process of transition from children’s services and education to adult services should involve. They saw the prospect of transition as involving a need to fight, often alone, for their son or daughter’s welfare. Both groups felt they lacked sufficient information about what to expect or who should do what and when. The article presents a list of information requirements common to parents and young people alike (see Box A):

Box A

- What is transition? Who is involved? What are their different roles?
- What rights, entitlements and procedures exist at a national level?
- How is the transition process interpreted locally?
- How can person-centred choices be accessed locally? What services are available locally? What options might be developed for the individual young person through different agencies?
- What support is available to young people and families throughout the transition process and into adult life?
- Are there specific transition workers or key workers locally? Information was also needed to help young people, their parents and supporters to work through a range of

other issues, including:

- The changes occurring and their impact on family relationships (e.g. if a young person's benefit levels changed, as they left home).
- Adult rights and responsibilities.
- Empowerment and self advocacy.
- Increasing independence, including taking opportunities, safety and risk.

Specific information was also required on areas like work, going to college, where to live, money, friends, sex and relationships, safety, living independently, healthy living, emotional changes and having fun. The parents and supporters also suggested an additional need for information on changes in services.

(Tarleton & Ward, 2005, pp 73-4)

Research conducted by Pain (1999, see also Beresford 1994, Vernon, 1995, Dale 1996) with parents of young children with disabilities, and by others, found that personal communication by known and trusted individuals such as key workers and other staffs with close contact with their child was highly valued by parents. He cites Ley (1989), Peterson et al (1989) and Sandler (1989) as advocating that "all the necessary information should be covered verbally first before the use of printed material as a backup" (Pain, op cit):

"There were no substitutes for real people, written information is nice to have as a comfort factor, but you really get your information from people talking face to face with them"

(Parent with a child with learning disabilities, in Pain, op cit, p303)

Simply having information isn't enough. The experience of others in similar situations, who can give advice from a similar perspective, was also valuable, as was the advice of professionals who could guide changes in the management of the child. Not knowing what was possible, some parents had difficulties formulating questions, which did not mean they were not important to them:

"I think if somebody could have perhaps have come to the house, and been with you in the day-to-day dealings with a child like that, to help you learn how to cope. Because you just have to fumble your way through. And you don't always do what's best"

Parent of a child with learning disabilities, in Pain, (op cit)

Pain concludes with a point that is pertinent for parents of children of all ages:

"All parents need to know the implications of the child's disability for the family, and how they can fit what is being recommended as best for their child into family life. The obligation lies with health professionals to convey that information in a way the parent can understand..."

(Pain, op cit, p310)

Implications for a Guide to services for young people with learning disabilities and mental health problems

The experience of family carers of relatives with learning disabilities is still not well understood. This review found little research on how they perceive and work with professionals in mental health services, or how they understand 'mental health problems' (as compared with LD or behavioural problems).

To date much emphasis has been placed upon mothers – knowledge of how fathers and siblings understand their role as carers and their experiences of caring is very limited.

Any model of caring must take into account the policy context of service provision (including the politics of service provision) as well as consideration of individual behaviours and strategies used by parents to 'cope'. Failure to take into account issues of social inequality, particularly differences in the levels of power experienced by parents and professionals, is likely to result in explanations that are narrow, paternalistic and pathological.

References and Further Reading

Beresford, B. (1994) *Positively Parents: Caring for a Severely Disabled Child*, SRNU, London, HMSO.

Birenbaum A. (1971) The mentally retarded child in the home and the family life-cycle. *Journal of Health and Social Behaviour* 12, 55–65.

Blacher, J. (2001) 'Transition to adulthood: mental retardation, families and culture', *American Journal on Mental Retardation*, 106(2), 173-188.

Case, S. (2000) Refocusing on the parent: what are the social issues of concern for parents of disabled children? *Disability and Society*, Vol 15, No. 2, 271 - 292.

Case, S (2001) Learning to partner, disabling conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities, *Disability and Society*, Vol 16, No. 6, 837-854.

Clegg, J., Sheard C, Cahill J, Osbeck L. (2001) Severe Intellectual Disability and transition to adulthood. *British Journal of Medical Psychology*, 74, 151-166

Dale, N., (1996): *Working with Families of Children with Special Needs: Partnership and Practice*, Routledge, London.

Department of Health (1996) *Community Care and Direct Payments Act*, The Stationary Office, London.

Department of Health (1999) *The Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003*, The Stationary Office, London

Department of Health (2003) Community Care and Direct Payments Act, The Stationary Office, London

Department of Health, (2005) Green paper: Independence, Well-being and Choice: our vision for the future of social care for adults in England, London, The Stationary Office

Drake, R. (1992) Consumer participation: the voluntary sector and the concept of power, *Disability, Handicap & Society*, 7, pp. 267-278.

Felce, D. & Perry, J. (1995). Quality of life: its definition and measurement. *Research in Developmental Disabilities* 16, 51–74.

Felce, D. & Perry, J. (1996a). Exploring current conceptions of quality of life: a model for people with and without disabilities. In: *Quality of Life in Health Promotion and Rehabilitation - Conceptual Approaches, Issues and Applications* (eds R. Renwick, I. Brown & M. Nagler), pp. 51–62. Sage Publications, London.

Felce, D. & Perry, J. (1996b). Assessment of quality of life. In: *Quality of Life. Vol. I: Conceptualization and Measurement* (ed. R. L. Schalock), pp. 63–72. American Association on Mental Retardation, Washington, DC.

Goupil, G, Tasse, M, Garcin, N, Dore, C (2002). Parent and teacher perceptions of individualised transition planning. *British Journal of Special Education*. 29 (3), 127-135

Grant G. (1993) Support networks and transitions over two years among adults with a mental handicap. *Mental Handicap Research* 6 (1), 36–55.

Grant, G., Ramcharan, P., (2001) Views and experiences of people with intellectual disabilities and their families (2): The family perspective, *JARID*, 14, 364-380

Hendey, N. and Pascall, G. (2001) *Disability and Transition to Adulthood: Achieving Independent Living*. Brighton: Pavilion.

Heslop, P., Mallett, R. Simons, K. & Ward, L. (2002) *Bridging the Divide at Transition. What Happens for Young People with Learning Difficulties and their Families?* Kidderminster: British Institute of Learning Disabilities.

Kim, H.W., Greenberg, J.S., Seltzer, M.M., and Kraus, M.W (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 47, 313-327

Mcgrath, M., Grant G., (1993) The Life Cycle and Support Networks of Families with a Person with a Learning Difficulty. *Disability, Handicap & Society*, Vol. 8, No . 1, 25

McNair, J. & Rusch, R. (1991) ‘Parent involvement in transition programs’, *Mental Retardation*, 29 (2), pp. 93-101.

- Mitchell, P. (1997) The Impact of Self-advocacy on Families Disability & Society, Vol. 12, No. 1, 1997, pp. 43 – 56
- Orlowska, D., (1995) Parental perception in issues concerning their sons and daughters with learning disabilities Disability & Society, Vol 10 No. 4 437- 456
- Pain, H (1998). Coping with a child with disabilities from the parents' perspective: the function of information. Child Care, Health and Development, 25, 299-312.
- Pascall, G., Hendy, N., (2004) Disability and transition to adulthood: the politics of parenting, Critical Social Policy, Vol. 24(2), 165 – 186.
- Petry, K., Maes, B., Vlaskamp, C. (2005) Domains of Quality of Life of People with Profound Multiple Disabilities: the Perspective of Parents and Direct Support Staff, Journal of Applied Research in Intellectual Disabilities, 18, 35–46
- Riddell, S., Wilson, A., Adler, M., Morduant, E., (2002): Parents, professionals and special educational needs policy frameworks in England and Scotland, Policy & Politics, Vol 30, No 3., 4311 – 425.
- Row, S. (2005) Surviving the Special Needs Education System: How to be a Velvet Bulldozer, London, Jessica Kingsley Publishers.
- Rowland-Crosby, N., (2003) Developing Connexions - Young people with disabilities, mental health needs or autism, London, Foundation for People with Learning Disabilities
- Seltzer M. M. & Krauss M. W. (1989) Ageing parents with mentally retarded children: family risk factors and sources of support. American Journal on Mental Retardation 94, 303–312.
- Smart, M. (2004a). Transition planning and the needs of young people and their carers: The alumni project. British Journal of Special Education, 31 (3), 128-137
- Smart (2004b) Transition Planning and the Needs of Young People and Their Carers – The Alumini Project: Summary of research findings
- Tarleton, B., Ward L., (2005) Changes and choices: finding out what information young people with learning disabilities, their parents and supporters need at transition, British Journal of Leaning Disabilities, Vol 33, 70-76, Kidderminster, BILD Publications.
- Thorin, E., Irvin, L. (1992) Family stress associated with transition to adulthood of young people with severe disabilities, Journal of the Association for Persons with Severe Handicaps, 17, pp. 31-39.
- Todd, S, Jones, S (2003) Mum's the Word: Maternal Accounts of Dealing with the Professional World, Journal of Applied Research in Intellectual Disabilities, 16, 229 – 224

Todd, S., Jones, S., (2005) Looking to the future and seeing the past: the challenge of the middle years of parenting a child with intellectual disabilities, *Journal of Intellectual Disability Research*, Vol. 49, Part 6, 389-404.

Townsley, R (2004) *The Road Ahead: What does the literature tell us about the information needs of young people and their families at transition?* Bristol, Norah Fry Research Centre.

Turnbull, H. (1988) The challenge of providing comprehensive support to families, *Education and Training in Mental Retardation*, 23, pp. 261-272.

Turnbull H. R., Behr S. K. & Tollefson N. (1986) Positive contributions that persons with mental retardation make to their families. Paper presented at the AAMD Conference, Denver, CO.

Turnbull H. R., Guess D. & Turnbull A. P. (1988) Vox populi and Baby Doe. *Mental Retardation* 26, 127–132.

Vernon, J., (1995): *Putting Children First: Developing Policy and Practice for Children with Disabilities in Hackney*, Council for Disabled Children, London.

Ward, L., Mallett, R., Heslop, P., Simons, K. (2003) Transition planning: how well does it work for young people with learning disabilities and their families? *British Journal of Special education*, Vol. 30, No. 3, 132 – 137.

Watson, D., Lewis, M., Townsley, R., Abbott D., Cowen, A., (2004) *All Together Better: a guide for families of a disabled child with complex needs*, Bristol, Norah Fry Research Centre

White N., Hastings R.P., (2004) Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities* 2004, 17, 181–190

Williams et al (2003). Paying the Piper and Calling the tune? The relationship between parents and direct payments for people with intellectual Disabilities. *Journal of Applied Research in Intellectual Disability*, 16, 219-228.